



REALTIME FILE

Drexel
The 8th Annual Autism Public Health Lecture
Tuesday, December 1, 2020
11:00 AM

CAPTIONING PROVIDED BY: ALTERNATIVE COMMUNICATION SERVICES, LLC
WWW.CAPTIONFAMILY.COM

COMMUNICATION ACCESS REALTIME TRANSLATION (CART) IS PROVIDED IN ORDER TO FACILITATE COMMUNICATION ACCESSIBILITY. CART CAPTIONING AND THIS REALTIME FILE MAY NOT BE A TOTALLY VERBATIM RECORD OF THE PROCEEDINGS.

>>> Hello and welcome to the 8th annual autism public health lecture. I am Diana Robins director of the institute. Today is our first virtual all Tim public health lecture. Although I am sad that we cannot come together in person, the positive outcome is that people are attending who may not have been able to come to campus so I welcome all of you.

I also want to thank the outreach corps for organizing this lecture.

Formed in 2012, the A.J. Drexel autism institute was the first autism research center to focus on public health science. Our mission is to understand and address the challenges of autism by discovering, developing, and sharing population level -- and community based public health science. Our institute houses three research programs. The modifiable risk factors is program is led I did Dr. Diana Shendle, the early detection and intervention program is led by me and the life course outcomes is led by Dr. Lindsay Shae who leads the analytics sector.

We are supported by three corps. The clinical core is led by Dr. Elizabeth Sheridan, the outreach core is led by Dr. Jennifer plumb and finance and administration services are led by Christine Jacko. Currently we have 54 faculty and staff in the institute and we also work with students and trainees from several Drexel schools and colleges.

Through the years, our autism public health lecturers have showcased many different voices from the research perspective. We aim this presentation at a broad community audience. So today, we are excited to add a new voice.

That of Julia Bascom, the executive director of the autistic self-advocacy network. As we continue to grow and deepen our community engagement, we will continue to highlight the diverse perspectives that enrich our commitment to public health science. We would like to thank Julia for her presentation today. We would like to thank mayor Kenny and Senator Bob Casey's office for joining us today for this important discussion on the discussion of policy in autism.

I would like to introduce Dr. Lindsey Shay who will kick off today's lecture.

>>> Thank you Diana and thank you all for being here. We will get us started with the welcome from our city mayor, Mayor Kenny.

>> Hello, I'm Mayor Jim Kenny. We are proud of the robust research that's going on throughout our city. The A.J. Drexel autism institute has a unique take as the first research organization built around a public health approach to understanding and addressing the challenges of autism, spectrum disorders. I look forward to the advancements that will be made in autism research right here in Philadelphia in the coming years, including today's autism public health lecture by Julia Bascom. Together we can continue to make our city a more inclusive place for everyone. Thanks for being here.

>> [Lindsey] and to continue to highlight the great work that's ongoing in Pennsylvania and in Philadelphia, we have been proud through the policy and analytics center and the collaborative funded by the Pennsylvania Department of Human Services, Bureau of Supports for autism and special populations, to partner with the autistic self advocacy network to create a self advocate's guide to Medicaid, which is available. This is one of the most popular across platforms available in a variety of plain language as well as easy-to-read versions and includes a variety of information about the Medicaid system and navigating the services that are included.

Both the Philadelphia autism project and the collaborative offer web based platforms to learn about and access self advocacy and support groups throughout the state and the city. They are available on the ASERT collaborative which is paautism.org and Phillyautismproject.org and the options include online versions for all of us navigating the virtual world. Right now.

The Philadelphia autism project has a seed-funding initiative to help raise awareness of autism and kick off and sustain self advocacy and support groups many among other programmatic intent and a new round of applications for seed funding from across Philadelphia will be available in December. So check back at phillyautismproject.org. We have also been excited to

partner with community behavioral health to offer peer specialist model and anyone in that program can learn more at phillyautismproject.org/peer. >>> The life course outcomes program has a mission of building a base of knowledge about social determinants that influence services and outcomes across the life course.

To achieve this goal, we work on population level data, program models, community building models, and collaborative community problem solving.

Today, the life course outcomes research program has a new national autism indicators report available focused on health and health care. And you can access that report along with all the other national autism indicator reports at Drexel.edu/autism_outcomes.

This report authored by Jessica Rast has a variety of really robust data sources gathered from multiple geographic locations and looking at a wide variety of health outcomes and needs. That can point us to ways we can continue to develop community based programs and policies to address where programs and policies are needed.

And with that, I am going to hand off to Michael Gamel-McCormick, the policy director for Senator Bob Casey. Michael?

>> Thank you very much. It's an honor to be here. I want to thank the Drexel Autism Institute for inviting me and to introduce the keynote speaker for the 8th annual autism public health lecture. Thanks, too, to Dr. Diana Robins and the leadership team at the institute for continued work and commitment to public policy implications of research being conducted through the institute.

And Lindsey, a special thank you to you, too. Your leadership and your clear communication I think makes the work of the institute more effective and more resonant and I greatly appreciate it.

My boss, Senator Bob Casey, sends his greetings and his appreciation of the work that the institute does. Not only in Philadelphia and Pennsylvania, but it has an impact throughout the world. And we should be exceptionally proud of that. For it to be located here in Philadelphia. And in Pennsylvania.

When my previous boss, Senator Tom Harkin retired from the senate, he passed along the NIH appropriations portfolio to Senator Casey.

Since that time, Senator Casey has worked to increase funding for the national institutes. He's done so, however, in a quiet way, but also in a way that includes another policy implication. And that's to make sure that there is a strong disability voice among the decision makers within

those institutes.

He works from a point of view that we have to make sure that people who consume services actually have some voice within those services. And that brings me to a few points about disability public policy that I would like to make before introducing the keynote speaker.

My plan had been, up until last night, to provide a pretty standard reflection on the status of disability policy in Congress. Especially as we are having a transition to a new administration. And to a new session of Congress itself. But I scrapped that plan last night when I received a note from a service provider advocate.

Now much of my work involves listening to people. All sorts of folks. Constituents, stakeholder, advocates, family members all across the board. Many of them come in to visit or at least during the last nine or 10 months, they Zoom in to visit with datas and stories. They come with information that they have gathered locally, sometimes there are researchers who come in. And a lot of times what people do is they come in and they bring thoughts or quotes from other leaders or often from politicians, as well.

And the note I got last night, it closed with a message from Vice President Hubert Humphrey shortly before he died. It's a quote that I hear often. It ends up in disability literature and sometimes even people say it at the end of a meeting that they are having with me.

The quote's from 1977. So it's 43 years ago. And this is what Vice President Humphrey said. He said -- the moral test of government is how that government treats those who are in the dawn of life, the children, those who are in the twilight of life, the elderly, and those who are in the shadows of life, the sick, the needy, and the handicapped.

I am pretty sure that when it was said, it was said with the best of intentions and with empathy and probably with some love, as well. The quote is used to empathize, or emphasize, the lack of focus or investment and needed supports for older adults, for disabled Americans, and for the lack of investment in prevention services for young children.

That is what those who use it often tell me that I ask why they have chosen it in their literature or meetings. Last night, though, I read it and I reflected and I stepped back and I thought I'm troubled by this quote. There's something in it that doesn't feel right to me.

And for me, it's troubling because of what it says about the people who comprise the groups identified in the quote. Those disabled Americans,

older Americans, young children, those who are sick. It also troubles me because of what it doesn't say about them. First, if you look at that list of people, it comprises about 50% of the U.S. population. If we use some census figures, some rough census figures say from 2018, there are about 75 million children in the country. There's about 55 million people over the age of 65. The CDC estimates there are about 61 million adults who are disabled, and there's 40 million people who live in poverty because their earnings are so low. That doesn't even include the largest group that he mentioned. That's those with chronic health conditions or what he calls the sick. That's almost 133 million people in this country.

If we do some quick back of the envelope estimates, the groups the former Vice President mentions probably total somewhere around 175 to 180 million. Of the people living in the United States today. Recognizing that there's a bunch of intersectionality across those different groups. But even if that's an underestimate, that's more than half of the country.

What's troubling about the quote for me is that it infers the thought that the people who make up these groups need to be spoken for. They need to be looked after. And that they can't stand up for themselves. No matter how well meaning, there's an inherent paternalism in the statement. A paternalism that's directed toward over half the country.

I don't believe that they can't speak for themselves and I don't believe that they can't make decisions for themselves. The perspective from the quote says that those who make up those groups have no power. That they don't have agency of their own and they must be spoken for by others who do have power.

It assumes the members of these groups must be granted access because they do not have the power to have access on their own. And sadly, from a public policy perspective, the assumption of lack of access and the lack of voice isn't necessarily wrong. As if I haven't done enough of a digress, let me digress just a little bit more for a few moments here.

The bones of our representative democracy, a declaration of independence, the Constitution, and its amendments, in many ways are wonderful. But our founding documents are not about inclusion. They are really about how to keep power concentrated in the hands of a few. And in 1787 if you were a woman, if you were Black, if you were brown, if you were not Christian, if you owned no land, and most of all, if you were a native person, our founding documents were devised to bar you from having a voice and from having access to resources.

Now the good thing is, is that the bones of those documents actually allow

for some hope. Not all is lost. And what's happened over the last 233 years has really been a struggle for inclusion. To gain access to recognize agency and to acquire some power in what happens in our country. But that road is really long and rocky. Let me take just a really quick example here.

Something that we take for granted is voting. In our country, access to voting is emblematic, however, of the centuries-long fight to gain a voice in the government structures that represent us. It wasn't until 1870 that Black men were granted the vote. A right embedded in the Constitution when the 15th amendment was ratified. But quickly states put in place new barriers to deny Black men the right to cast a vote. Those Jim Crow laws persisted for another 194 years until 1965 when the Voting Rights Act was passed and signed by Lyndon Johnson.

Women, too, were denied the right to vote until a hundred years ago when the 19th amendment was ratified in 1920. 133 years after the original Constitution was ratified.

And if we look at people with disabilities, well that really is a story of continuous barriers and lack of access to voting. Disabled people should have been afforded the right to vote under 14th amendment. If there are laws related to voting, that everybody gets the right to vote.

Those barriers weren't removed in 1973 when the amendments to rehabilitation act were passed that said all must be accessible to disabled Americans. Those barriers were not removed when the Americans with Disabilities Act was passed in 1990 and those barriers were not removed when the help America vote act was passed. Three significant laws, one major amendment, have all attempted to make voting accessible to all disabled Americans. And unfortunately, at this time, have not been successful.

Now for sure, things are much, much better than they used to be in 1787 or in 1887. But if you are unsure of how inaccessible voting is, just go to the 2017 government accountability office report that examined the accessibility of voting in the 2016 presidential election. That study found there were only 17% of voting sites examined that were fully accessible to people with disabilities. I'll say that again. 17% of the sites examined.

An additional study found that in 2016, the turnout rate for people with disabilities was 5% lower than for the general population. With a lack of accessibility of voting places and voting procedures, I am surprised the voting rate for disabled Americans wasn't even lower.

Voting. That most basic of democratic actions, that which is an act of power and engagement, is still not accessible to hundreds of thousands and probably millions of disabled people to this very day.

So at one level, Vice President Humphrey was correct. We do need laws to ensure equal access and treatment and we do need governments to enforce such laws. To protect and to take care of those who can be mistreated by the majority or by those in power.

But let me circle back as to why Vice President Humphrey's statement is disturbing to me. What troubles me is what is missing from the quote. About the people it aims to protect. What is missing is power and agency. What is missing is the acknowledgement that the members of those listed groups are knowledgeable and skilled and experienced and valuable. What's missing is the recognition that the members of these groups have the right to engage and invest and effect and control the policies and services they have to consume and the laws under which they must live every day.

The quote embodies a paternalistic approach to policy. An approach that marginalizes and infantilizes older adult, children, disabled people and those who are poor.

Hubert Humphrey is clearly concerned and empathetic but his words don't engender respect or acknowledge the fullness of the individuals in those groups that he points out. The statement reflects antiquated way to think about policy. One that does for, or speaks for, and delivers for groups of individuals. Often without asking those individuals what they actually want or need.

With great effort, and I think with some reflection and being reminded repeatedly, I hope we are turning away from this type of policy. We already have some decent examples of that. If you look at the federally funded centers for independent living, the requirements are that their staff must be comprised of at least 50% people with disabilities. The same requirement applies to the board of directors for those centers, as well.

If you go back to 2000, the developmental disabilities act and the Bill of Rights, the major programs in that particular act must have advisory boards comprised of at least 50% people with disabilities or family members. That isn't control or decisions about how funds are allocated but it's a step in the right direction.

And that direction we are moving toward is how to give away power. How to invite others to use power. And how to ensure decision making isn't

concentrated in the hands of a few. All of us, myself in my role as a senate staffer, my boss as a Senator who represents 13 million people, almost 2 million of whom have a disability, the CEO of nonprofit agencies, the president of a University, are any and all of us who controls funds and services and policies. We need to reflect on how we see the people we work on behalf of do we see them as people who receive something or do we see them as partners? And do we ultimately see them as individuals and a need to take over the process of what is being provided for them?

When I read the note -- when I read the note from the advocate last night and read Humphrey's quote probably for like the 100th time, I saw the good in it. The desire to make resources available to those who need the support. But I also looked closer and saw what the assumptions were. And included in those assumptions are sentiments. Intentional or not, that limit people that assume noncompliance and restrict opportunity.

If we are in a place where we have power, resources and control, we should every day reflect how we use those resources. And how we can make work to make it available to others. And more than that, we should be thinking about how we release those resources. So that those who need them have control over them.

And with that final thought, let me transition to introducing you to somebody who works every day to create a truly inclusive world. I am honored to introduce to you the keynote speaker for the 8th annual autism public health lecture. Julia Bascom is the executive director at the autistic self advocacy network. She assumed the role as executive director from one of the founders. That's not an easy task. Originators have strong, strong feelings about their organizations and taking over from one is very difficult. I have had the privilege of watching miss Bascom build ASAN into an organization that's disciplined and thoughtful and in many ways revolutionary. She's constructed an organization that supports grassroots efforts to improve the lives of autistic people across the country. She also has ensured that the same organization has the capacity to engage in and affect state and federal policy. Accomplishing both of those things is no easy feat. Miss Bascom has also reached across the disability community to create collaborations and alliances among disabled groups, making the community stronger. And more effective.

You may think that cross disability advocacy is logical and it certainly is. It's also very, very difficult. She works to achieve that goal of collaboration. In a world that was and in some sectors continues to be dominated by organizations headed by nondisabled executives coming from paternalistic care-taking perspectives, she has worked to find common ground while remaining steadfast about both representation and power.

Now if you are not keeping track, that's three daunting tasks at which she has been extraordinarily successful. Julia makes the disability stakeholder community a better and stronger place. And that means that she makes the world a better place. I am honored to call her a colleague. And so I introduce to you your 2020 autism public health lecture keynote speaker, miss Julia Bascom.

>> Hi. Thank you so much for having me and thank you, Michael, for that incredibly powerful and incredibly kind introduction. Like Michael said, my name is Julia Bascom. I am the executive director for the advocacy network. We are a national disability rights organization run by and for autistic adults and people of other developmental disabilities. I want to take a moment to give you all some background on my organization before we get started. Because we are different from other autism organizations in a few key ways. First, we are a self advocacy organization. And that means two things. One, it means that we are run by and for autistic people. That means me, my staff, my board, are all autistic people often with additional disabilities as well. Two, like I mentioned, self advocacy means we are a disability right organization. We take a civil rights framework to disability issues. We don't think about disability policy as a set of medical issues. We frame things in terms of inclusion and equity and justice.

ASAN believes that the goal of autism advocacy, policy and research should be a world in which autistic people enjoy equal access, rights, and opportunities. Our work focuses on policy advocacy and systems change, as opposed to things like family support or direct services to local folks. That work is important, but it's not what we do. Similarly, we focus specifically on adults who tend to be overlooked in our cultural conversation about autism.

Now by this point, I know that some folks have start aid assuming that when I talk about rights and policy and self advocacy I really just mean rights and policy and self advocacy for people like me. And people like me can mean a lot of different things. But for brevity's sake, with let's say it means autistic people who can talk sometimes and who don't have an intellectual disability. I am going to talk more about what I mean when I say rights and policy and self advocacy but I want to be absolutely unambiguous and clear right from the start that I am talking about all autistic people. ASAN includes and works on behalf of the entire autism spectrum. A third of my board are AAC users. We include in our advocacy people who have intellectual disabilities, people who can't live on their own, people who struggle with self-injury or aggressive behavior and people with additional disabilities and complex needs. Not a single thing I am about to say is for one segment of our community. ASAN believes that civil

rights are for everyone. That's what we are all about. So that's self advocacy in a nutshell. Next slide, please.

Another word for all of these ideas is neurodiversity. Neurodiversity is just two words smushed together to make one. Neurological, and diversity, combined to make Neurodiversity. And on its face, Neurodiversity is a simple biological fact. Reflection of reality. No two human brains are exactly the same. Even on a macro level, there are lots and lots and lots of different ways to have a brain. Some of those ways are called autism dyslexia, left handedness, perfect pitch and so on and on and on. But Neurodiversity is also a powerful, philosophical and political idea. The developmental disabilities act states that disability is a natural part of the human experience. This is federal legislation introduced in I believe the '70s and last authorized in 2000 which recognizes that neurological diversity, that disability, is normal. It's a basic fact about our species. And that comes with consequences. The law goes on to say disability is a natural part of the human experience that does not diminish the right of the individuals with developmental disabilities to enjoy the opportunity to live independently, enjoy self determination, make choices, contribute to society, and experience full integration and inclusion in economic, political, social and cultural and educational mainstream of American society.

In the Neurodiversity movement of which I and ASAN are very much a part is about making that promise a reality. It's about embracing the simple biological fact that there are many ways to have a brain, inclusive and fair to everyone regardless of how their brain works. We absolutely believe that autism is a disability but we also know that disability itself is very different from what most people think. Disability isn't a tragedy. A worst-case scenario or a horror story. Disability is a natural part of the human experience.

I want to dig into what that means. There are a lot of different ways to think about disability. If we are philosophers, then those different ways of thinking are called models. The charity model, the moral model and so on. Whole books have been written about this. I am personally not a philosopher, so I am just going to talk about the two most common models. The medical model and the social model. Both the medical and the social model of disability look at the person with a disability in the world and they identify a problem that needs to be solved but they focus on very different things. So for the purposes of this example, let's say our person with a disability can't walk. So they use a wheelchair. And they have encountered a plate of stairs which they can't get up. If we are using the medical model, we look at the scenario and we identify the problem pretty quickly. They can't walk. Their legs don't work. And once we

have identified the problem, we can work from there to identify potential solutions. Maybe they need fiscal therapy or surgery. Maybe we need to look into different treatments for spinal cord injuries. Maybe stem cells are doing something cool. Maybe there's a new drug. The possibilities are endless. Although they definitely involve some people in white lab coats.

So that it's the medical model. The social model sees the same person. Here's our guy. He cannot walk so he uses a wheelchair and he's encountered a flit of stairs. He cannot go up the stairs. And that's not good. But the social model identifies a different problem at the root of all of this. Why didn't anybody build a ramp? Instead of locating the problem as being within the disabled person's body, the social model says that the problem is in how we, as a society, treat people with disabilities, people with different brains or bodies. Since the problem we have identified is different, the solutions are different, too. The social model says we should be looking at a disabled person as a whole person who interacts with the whole world. We should identify the personal barriers that are getting in their way and focus on removing them. We can apply this way of thinking to autism. In the medical model, autism means that my senses are disordered. If sounds muter me, the solution is to fix how my brain is processing those sounds or to teach me to get used to it or at least how to hide my discomfort. The problem is located in my body and what my body does. In the social model, the solution to auditory overload is to give me a pair of headphones. The social model also allows us to being acknowledge complexity. The same painful sensitivity might also make my experience with music uniquely transcendent. The same thing that makes wool unbearably itchy, might also Mike water between my Fingertips more soothe soothing than anything else in the world. Maybe not all of those things need a solution. May autism might need a more nuanced approach that's been traditionally offered. The social model isn't something that Neurodiversity advocates made up. It comes out of the broader disability rights movement of which we are a part. The disability rights movement has a long and complicated history, but for simplicity's sake, I will say that the modern disability rights movement in the United States by the 1970s was driven by people with physical disabilities and often serious medical needs. People with cerebral palsy, post-polio syndrome, muscular dystrophies, et cetera. Our leaders were people who often needed 24/7 care. And yet, they were focused not on medical advances but on identifying the artificial barriers imposed on them by a society that didn't value accessibility. Similarly, the self advocacy move meant was created by people with intellectual disabilities who were institution survivors. They were not asking for some sort of flowers for Algernon scenario. Their demands were very clear. Start treating us like people. Stop calling us the r-word, and stop keeping us in institutions.

I want to stress that the social and the medical models of disability are not either/or. When I break my arm, I want the emergency room doctors to use the medical model. But autism is not a broken arm. It's a lifelong Neurodiversity condition that colors and influences every part of how I interact with the world. Because my brain is very different in important ways from the norm, we call it a disability and this world is not built for me. Similarly, sorry, because our world expects fluent verbal speech at all times and is filled with loud noises and big crowds of people and unpredictable schedules, it can be inaccessible to me. I might as well be sitting at the bottom of a flight of stairs I cannot climb. I'm disabled. That doesn't mean there's something bad or wrong or deficient about me that needs to be changed. It means that a world dominated by people who love eye contact puts barriers in my way. I'm not sure what it would look like to take all those barriers away, but that's what we will talk about today. I am going to focus on two main buckets of barriers. Research and policy. I am going to talk specifically about the importance of 'tis a tory research and policy making and again these are not new ideas that I came up with by myself. The rallying cry of disability community for many years has been nothing about us without us. This is a passionate cry for equality but also a logical proposition. If the goal is to remanufacture barriers we experience, we should be a part of that conversation. No one knows the barriers better than we do. So let's talk. Next slide, please.

Public policy is fundamentally the process of making decisions about how public dollars should be spent. We write laws deciding what should and shouldn't happen. And then regulations explaining how to implement those laws, and typically in order to have an impact all of this comes with some sort of monetary implication. Are we spending money on a new program? Are we no longer spending money on something? Are we attaching strings to the money? Even basic laws like murder is illegal have a fiscal component. The criminal legal system to enforce those laws doesn't run without it. If our goal is to craft effective policy, it's really important to remember that. Policy advocacy is ASAN's bread and butter. What that means is we spend a lot of time looking at the laws and regulations that make up our current interlocking system of programs and policies affecting people with disabilities. We look at housing, employment, criminal justice, health care, guardianship, education and a lot more. We look how all of these pieces fit together and the history of how they came to be and we look for the levers. The things that mean that these laws and regulations do or don't get enforced. What is being funded? And why? What strings are attached to that funding? If we change anything about this system, what is the impact? What are the ripple effects? And then we take our knowledge about what our community needs and deserves. And we combine that

with all of this analysis. And we put forward proposals to change things for the better.

So for example, a lot of people with intellectual and developmental disabilities including a fair number of autistic adults currently make less than minimum wage. A lot less. Sometimes five cents an hour. This is because of a loophole in the Fair Labor Standards Act passed in 1938. It gave workers a right to a minimum wage, but it made an exception for people with disabilities. This was originally thought of as a way to incentivize employers to hire people with disabilities. If they have to pay us less money, maybe they will be more likely to hire us. Nowadays, it's obviously an incredibly regressive and discriminatory and degrading process. But the law hasn't changed. That means there are still a couple hundred thousand people with disabilities, mostly people with intellectual disabilities in this country who are making literally pennies on the dollar. Some of them are right here in Pennsylvania.

ASAN thinks this is a big problem. So does every other self advocacy organization and virtually every other disability organization in general. We think this loophole needs to be closed, that people need to be paid real wages for their work, and that instead of being stuck in segregated places like sheltered workshops, we should get support to work jobs that are meaningful to us in the broader community. If I had my way, I would snap my fingers right now and that's where we would be. But since this exception has been allowed for over 80 years, a tangled policy web has grown up around it. If we want to end subminimum wage, we need to address all of those problems, too. So for example, most people who earn minimum wage work in sheltered workshops. Sheltered workshops are segregated settings where large groups of disabled people spend all day together and don't really get a chance to interact with nondisabled peers or explore the broader community. These sheltered workshops are often primary activity during the day and might even offer transportation. If we end subminimum wage and close sheltered workshops we need to make sure that people have other things to do during the day. We need to make sure we are paying for personalized supports, including transportation so people can have good lives and family members don't have to stop working to stay home with us. Also, many people with intellectual disabilities can't just go through a typical hiring process and work a typical job without any support. We need to make sure we are investing in supported and customized employment so that people can really work. The good news is we know how to do these things. There's a lot of research backing this up. That's why ASAN enthusiastically supports the transition to competitive employment act as introduced by Senator Casey. This bill phases out subminimum wage over six years and gives states and providers resources. It adds funding to address complications. It helps states redirect their Medicaid funding

to meet people's needs in the community and it makes real investments in increasing the number of providers who do offer supported employment. It looks at all of those interconnecting pieces and it offers a real solution.

ASAN has a lot of different policy priorities beyond employment and I'll talk about a few of them today. Our guiding principle is self determination. The idea that people with disabilities including people with the most significant disabilities, have the right to be in charge of our lives, our so, and our futures. This idea is deeply connected to self advocacy. And so in that spirit of nothing about us without us, we are, therefore, big believers in participatory policy making. Next slide please. On some level, participatory policy making is a fancy word for democracy. That people have a hand in shaping it. It's o key to developing good policy solutions. No one knows an issue better than the people living it. But for people with disabilities, especially for people with cognitive disabilities, policy is often developed without even a thought of consulting us. We aren't seen as people you can ask about this stuff.

If any consultation happens, it tends to be through a third party. Parents or providers and not us. This is a problem because while the views of those groups are certainly valuable and should be included where appropriate, we are not in fact interchangeable. We often have different experiences, different perspectives, and different goals. There is no institute for self advocate voices. You have to talk to us.

For self advocates, participatory policy making often involves doing things differently from the norm. Self advocates have powerful lived experience, but we might not know the jargon that policymakers use. Information about policy issues might be inaccessible to us and traditional methods of consultation might not work. We might need adapted materials or information presented to us differently, extra time, communication supports, and a lot more. We might not be able to hold a traditional meeting or sending in formal couldn't meanies. Including us in the conversation can take a lot of work especially if the goal is for us to meaningfully contribute instead of just sitting there as a token disabled person. Pour meaningful inclusion is both a moral imperative and a necessary essential part of crafting, passing and implementing good policy. So ASAN has invested a lot of time and energy into figuring out how to make this work. I'm going to drink some water really quickly.

So for example in 2017, the president and Congress tried to repeal the Affordable Care Act and gut Medicaid. We wanted to protect those vital health programs and make sure people's intellectual and developmental

disabilities were able to participate in the national conversation about this. But we realized pretty quickly that a lot of people who depended on these programs to survive, especially Medicaid, didn't know it. And they didn't have access to information they could understand about what those programs were, how they worked, or what some of proposed changes would mean. So we worked together with ASERT to create tool CSU kits with this information. After months of work we were able to explain basics of Medicaid at a 4th grade reading level with visual supports. As a result, more self advocates with intellectual disabilities were able to follow what they were hearing in the news, form an opinion and express that to their elected officials. The Medicaid toolkit fundamentally changed the way we do advocacy. Three years later, we have created similar guides to employment policy, the federal budget process, voting, the Americans with Disabilities Act, home and community based services and talking to your elected officials and we are working on several more as we speak. Our goal is to create a conduit between self advocates and policy makers, providing the necessary support and infrastructure folks may need in order to be a part of the policy process. We are very focused on making sure that people have the tools and information that they need to participate and to share their views.

So that's one example. But participatory policymaking can look like lots of different things. Every state in the United States has a council on developmental disabilities. Often called the D.D. council for short which advises the governor on disability issues. D.D. councils are required to have robust participation from self advocates and they have often played a key leadership role in developing accommodations and strategies to support people with intellectual disabilities and policy meetings. For example, you might hold a pre-meeting to go over information on the agenda ahead of time or designate a go-to person that people can rely on for guidance and support. Or, you know, self advocates have been meeting in our own local groups for decades now and we even have our own state and national conferences. Policy makers can come and meet us where we are. We certainly go and meet them on their turf often enough. Data like this, about people's lived experiences, their expertise and recommendations, their insight into how things work on the ground, is crucial to making effective policies that help instead of hurt. Another invaluable form of data for policymakers comes from traditional research. Next slide, please. Thank you. Policy makers have a multi-faceted approach to research. They need research to craft effective policy, they need research in order to know how much different policy options might cost and how well they can be expected to work, how to maximize different outcomes and how to balance competing priorities and they also often fund research which is ironically in and of itself a policy decision. What research do we fund and how much?

We now have over four decades worth of research showing us unambiguously that people with developmental disabilities have better lives in our community than we do in institutions. This is true no matter what our disability is or how much help we need. When we are in the community, we are healthier, we live longer, we are happier, we gain more skills, and we achieve better outcomes. This has been proven over and over again. For policy makers, this is very important information. It has immediate policy implications. It means that when we think about services for people with disabilities, we need to be focused on supporting people that lived in the community. It means we should finish closing institutions. It means if we don't fix our service system, people are going to have a lower quality of life. And that's not acceptable.

But even with this knowledge, when we write policies about community living, we encounter new questions. For example, how do we know if a setting is truly in the community? We have very strong research that shows that a person who lives in a 10-person group facility has a very different quality of life. And on average a much lower quality of life than a person who lives on their own or with a friend or a family member. How do we draw that line between institutions and community settings? What do quality community services look like? What sets them apart from other services? How can we replicate them at scale across the country? These are critical issues that directly impact the day-to-day lives of millions of people with disabilities. We need to be able to answer them and we need to have laws and regulations and ultimately services that reflect those answers. We know that there are hundreds of thousands of people with disabilities sitting on waiting lists right now. They need services, but they aren't getting them. And then we know that there is some number of people, but we don't know how many, who don't get Medicaid or who don't meet criteria under a state's waiver, but who also still need services. Let's say that I want to write a law that would guarantee home and community based services to every person with a disability who needs them. I do. I want to write that law. I need to know how many people that will be. I need to know how many services I should be budgeting for. I need to know how much this bill will cost.

Policy makers need to be able to turn to researchers and get answers to those questions. In order to have effective policy and in order to be able to pay for that policy to be fully and comprehensively implemented, we need clear data. But when we look at the state of autism research right now, it becomes immediately clear that we have a big problem. Next slide, please.

The federal government spends over \$292 million on autism Republican er.

Year. Which represents over 80% of the total funding for autism research nationally. About 2% of research spending on autism looks at autistic people across the lifespan. Adolescents, adults and elders. Another 2% or so looks at services for us. What helps and what doesn't. In contrast, 48% of autism research funding looks at basic biology and what might cause autism. Typically with the explicit goal of preventing autistic people from existing in the future.

This does not reflect the priorities of the autistic community. In fact, we find this gross overbalance and the focus on prevention to be unethical and insulting.

It also doesn't help policy makers address pressing issues of relevance to our community. We have real urgent research questions that directly impact our quality of life and we would like to see these issues addressed. Autistic people die on average 16 years earlier than nonautistic people. What little data we have suggests it's largely due to preventable co-occurring medical preventions. Our suicide rate is nine times that of the general population. We have the lowest employment rate in the disability community. Research from right here at Drexel shows when we leave high school we are at incredibly higher risks of becoming disconnected from our communities, suffer incredibly poor outcomes as a result. Most autistic adults need some kind of long-term support over the course of our life. Few of us are eligible for Medicaid services. Nonspeaking autistic people can communicate if supported with communication methods besides speech. But there is very little known about the most effective methods or how to best support users. These are huge urgent issues. But autism researchers aren't focused on them. They aren't focused on them because that's not where the money is. Autism research dollars are concentrated at NIH and NIH wants to focus on traditional basic science. So that's where federal dollars go.

And that's a policy problem. It's a problem in the sense that it makes it harder for policy makers to write bills about services after high school or regulations about health care. But it's also a problem that federal autism research dollars are being spent so poorly. Will and that is something policy makers can do something about. That money is authorized by the autism CARES act. Congress could require more self advocate oversight of the money. They can move money from NIH to other research agencies that focus more on applied research. They could require NIH to balance spending or to put a certain amount toward issues identified as a priority by the autistic community. They could create pipeline programs for autistic researchers and that more funding goes to participatory research. Next slide, please. There are many different forms of participatory research. This is yet another area where we only have an hour so I am speaking very broadly. But in general we are talking about

participatory research, we are talking about shared power with researchers. We work together to pick the research topic, form research questions, design the study, analyze data, and discuss the results. Participatory research has a long history outside the autism community and it's a field unto itself. Right now, the most common response I see when the results of a new autism study are shared in my community is frustration. Sometimes, oftentimes, the frustration is because the research is of poor quality or focused on prevention or chasing the idea of a cure. But many other times the frustration is because the study is announcing something that something autistic people have known for a very long time. They could have just asked, we lament, as researchers breathlessly announce that stimming might be helpful or that autistic people sometimes experience anxiety. If autism research prioritized, we wouldn't be in the position where we are now where in 2020, researchers are starting to suggest that a lot of these autistic people really seem to have sensory issues. We could be decades further down the road. We might even have research based strategies to mitigate sensory overload.

There is real value to basic autism -- to basic science research and I'm not saying we should stop. But the point of autism science should be to help autistic people. It is worth asking us what we think would help and what matters to us. Autistic people, by and large, do not want a cure. We do not want therapies or medications which focus on making us appear less autistic. We don't want genetic tests that can diagnose autistic people before we are born. We want better health care. We want better services. If you want to stick to genetics research we want why some of us have connective tissue disorders or epilepsy. If you want to stick to pharmaceutical research, it would be great to get real data on how many of us react atypically to meds, any idea why, or how to get epilepsy or anxiety medications that actually work for us. If you want to stick to traditional psychology, that's fine. Help us develop a diagnostic assessment for adults because one don't exist yet.

No matter what field you are in, there are ways that we can work together and ways that your research can have a tangible impact on our lives. But that isn't what's happening right now. At Lech Walesa not to scale. And when the vast majority of autism Republican is looking at things that autistic people ourselves do not find valuable and, at worst, find harmful, we have a problem. The failure of autism research at large to take autistic people seriously is a moral failure just as it is in policymaking. It's also an imper cool field failure that holds the field back from meaningful insight and real impact. So, what does all of this mean? Obviously we have to change the way we do research, including our policies about research. We need to rebalance research funding and prioritize participatory research and focus on what the community record as a high

priority. Policymakers so far have failed to step up to the task. Autism CARES the law I talked about earlier was reauthorized about a year ago. We made small gains. There's language in there now acknowledging that autistic kids grow up into autistic adults and we managed to get one more seat for self advocates on the committee overseeing the spending. Now a whole 10% of the committee members might be self advocates. But Congress completely failed to address in any way the imbalance in research funding. To support other research agencies besides NIH or to prioritize participatory research or research on issues impacting adults or services. So that's not great. The next authorization is in 2024. And you can bet we are already gearing up to push for more changes. Again.

In the meantime, we continue to encourage researchers and funders to consult with the autistic community and we are happily engaged in uplifting research that does that. There are more and more researchers looking for creative ways to include our community in their work and we are excited to work with them. Increasingly, we are running into a newer problem where researchers come to us wanting to know what we think they are already so far along that it's too late for us to have a real input. We are trying to get folks to understand that participatory research much like participatory policymaking means coming to us before you have an idea much. It means coming together with the ideas from the very start. When we do that, we come up with better ideas. Which brings us back to policy. Just as with research, we have to change the way we do policy at a federal, state and local level. In fact, we have to change the policy process it is he. It currently has major barriers to autistic people and those with similar disabilities. Constituent engagement with elected officials often requires the ability to make phone calls, tolerate chaotic Town Halls or participate in formal meetings. That excludes far too many of us. Next slide, please. As an initial step toward changing that reality, ASAN launched our proxy caller system last year. With proxy calling, a constituent whose disability makes phone calls difficult can write out what they want to say to their Congressperson and a volunteer will make the call and read out their message for them. We have also hosted training for congressional staff to brief them on the system and to discuss other accessibility issues like what to expect when A.A.C. user calls. It's not a robocall. And how to better support constituents with disabilities. We are excited to see more and more congressional staffers themselves begin to identify as people with disabilities. Including some autistic staffers. The only thing more impactful than that would be to see more people with disabilities running for office. We working on that, too. This past month, Jessica Benham won her campaign as the first openly autistic candidate in the United States history in New York. Yuh-Line Niou won her reelection bid after coming out autistic as well. Nothing about

us without us includes the halls of power. A lot of folks believe that lawmakers have the only roles. They pass the laws and that's that. But in fact from a policy perspective, your job basically starts once the law is passed. Passing a law is a lot of work but you have years and years left to go once something is signed into law. Just about every disability related law needs regulations that go into more detail and even longer about what means to follow the law. Those regulations can take years to write and even longer to be implemented. Even once everything is up and running, it has to be monitored continuously to make sure that everything is happening properly. And what problems arise, we have to start that whole process over again. The good news for advocates is that none of this is supposed to happen without our input. Through the regulatory process, the government is supposed to give opportunities for public comment. Chances for experts, advocates, and everyday folks to weigh in and share our thoughts and our concerns and recommendations. Public comments can usually be provided in writing though sometimes they will be supplemented by Town Halls, listening sessions or other opportunities to share thoughts in person or over the phone. At ASAN, one of our next areas of focus is equipping to participate in the public comment process as well. The timeline is often longer than it is are fore events and format more flexible. We think it's a promising way for an impact shaping policy.

In order to engage, people need accessible information as well as the policies under discussion and how this connects to their life. We are working on creating those materials and are also looking to train other organizations to do the same. At the end of the day, our democracy is stronger when everyone can take part. That means that many different organizations, including those outside the disability community, are going to need to work on accessibility and inclusion.

A lot of the examples I use about the regulatory process are about the federal government. I want to make sure to note that it is also generally true of state and local government as well. Local advocacy is often more concrete for a lot of people. It can be easier to connect to your life. We need self advocates weighing in at every level of government and shaping policy wherever policy is made. As a national organization, I want people with disabilities to call their Congressperson. But I also want them to run for school board. School boards very rarely have people who went through the special education system on them. Imagine the impact.

At the end of the day, regulations and implementation or important because these things are a vital and necessary part of realizing the promises we made to the disability community. I am a part of the A.D.A. generation. I grew up after the passage of the Americans with Disabilities Act in a world where I theoretically had equal rights as a disabled person. As a

member of the A.D.C. generation, my life is quite different. I got to grow up at home, not an ins institution. I went to the neighborhood school, make my own decisions and my life looks pretty ordinary from the outside. But, like many members of the A.D.A. generation, I grew up learning firsthand the disconnect between what the law promised and what reality offered. Quick water break.

The A.D.A. promised us community integration, economic security, equal opportunity and full participation. This certainly the disability community celebrated the law's 30th anniversary with you but for many people with disabilities, even 30 years later, those promises have not been realize. If I live in a rural area and can't drive, I probably rely on my family and paratransit to get where I need to go. If my paratransit can't cross county lines or if it has to be booked days in advance and is always late, it's hard to say I'm really experiencing community integration. If I have to get Social Security in order to get Medicaid waiver services and Social Security forces me to live in poverty, economic security. If my guardian can forbid me to go to community events I'm interested in, that's not full participation. If company after company turns me away from interviews because they can tell I have a disability, I'm not getting equality opportunity. These are all policy issues. If we want to realize the promise of the A.D.A. and if we truly want equal access and rights for people with disabilities, we have to get involved. Lift up these problems and put forward solutions. And we have to use participatory policymaking to do that. For example, let's irk sell back to community living. Next slide, please. In 2014, C.M.S., which is the government agency in charge of Medicaid, released the final version of the home and community based services or HCBS. Settings rule. Prior to this regulation, there was not a standard federal definition of what home and community based services meant. Medicaid has two streams for funding long term services. One for services in institutions and one for services in the community. Without a clear federal standard for what HCBS meant, people were spending years on waiting lists for HCBS waivers only to receive services that were indistinguishable from institutional services. Living with many other people, following group schedules, rarely getting into the broader community and not getting supports that were truly individualized. It was a huge problem. In 2009, C.M.S. announced they were going to develop a regulation to clarify the difference and set minimum quality standards for HCBS.

The settings rule is a great example of the regulatory process in action. CMS held multiple public comment periods and got thousands upon thousands of responses from self advocates, service users, families, providers, states and just about everyone else. First they asked for general information. They wanted to know what folks experiencing the services

were, what was important to people and what everyone thought the rule should accomplish. They took all of that feedback and used it to make a draft. They put it out for comment again and got a ton of responses. There were things in the draft rule that people liked and things they didn't. They processed the comments and revised the rule again. Other government agencies funded additional research and outreach. ASAN and self advocates becoming empowered which is a national organization for people with intellectual disabilities received a grant to host a Summit and document what people thought good services meant for them. They put the results in a final report called keeping the promise which you can see on our website and made sure that was included in the comment process many

When they put the rule out in 2014, it reflected five years of intense work and advocacy. As a result, the rule focuses on the experience of the person getting services. Are we treated with dignity and respect? Do we have control over our everyday choices and schedule and routines? Do we have a person-centered plan? And is that plan being followed? It says we have rights like the right to eat when we are hungry, lock our door, and decorate our rooms the way we want to. I cannot stress enough how basic this regulation is. It gives us rights that other people take for granted. That's pretty much it. But if you have never had those rights before, it's huge.

And it's important to understand that the final settings rule was a compromise. Thousands of people commented and no one got everything they wanted. My organization, for example, wanted clear size limits on settings and we thought that the agency providing you services shouldn't be allowed to be your housing provider, too. We didn't get either of those things. Other people thought that providers should still be allowed to control what people ate and when they went to bed. They didn't get that. The final rule is hundreds of pages long and that's because CMS had to go through and respond to all the different comments they had gotten and publicly explain why they made the decisions that they did many at the end of the day, the settings rule is about program integrity. If a specific program is supposed to provide home and community based services and that program is being paid for with public dollars, then that program needs to actually provide what it says it does. Otherwise, that's Medicaid fraud. States can still provide institutional services but they need to make sure those services are being paid through the part of Medicaid that specifically funds institutions. There's no double dipping. By holding states accountable for how they are spending Medicaid dollars and making sure that people who are supposed to be getting HCBS are truly getting it, the federal government is protecting taxpayers, service and itself. It's basic good governance and it wouldn't have been possible without robust involvement from advocates including self advocates.

I'm spending so much time on this because I need you all to understand why this matters. Right now, it's still common for a person with a disability to have good services on paper, but to still be disempowered in their day-to-day life. Especially if they have an intellectual disability or significant personal care needs. Do we actually get to decide what we do every day? Do we have to follow special rules? Are we being treated like an adult? Who is really in charge of our day-to-day life? It should be us. It often isn't. This stuff can seem pretty abstract for folks who don't use services so I want to bring it home with a concrete example. Next slide, please. This slide shows image of my cat and I am going to explain why. I don't talk about my personal experience of disabilities very much in public. But I am going to make a small exception for this. I am an autistic person who can't live on my own. I use shared living for my residential supports and I am lucky to have a really good setup. For example, I have a cat. And that might not sound like a big deal. But listen. When I wanted to get a cat, I checked in with my roommate and then we went and got one. I didn't have to have a team meeting. I didn't have to get my group home or the agency to change the house rule rules to allow pets. I decided I wanted a cat and I got one. Like an ordinary person.

I need a lot of prompting or cuing and monitoring in Medicaid speak in order to complete some everyday routines. Especially my bedtime routine. By the time I'm willing to go to bed I'm so tired and it's hard to stay on task and I don't have much impulse control. I keep getting distracted by my cat and the cute things she's doing and forgetting that I was brushing my teeth or taking meds. My support person spends a lot of time during this redirecting me. Yes, the cat is very cute, remember to put the toothpaste on your toothbrush, that kind of thing. I get along really well with my support person, but an outside observer or a harried manager might say that I was wasting their time. Or maybe I'm stalling. I'm definitely having a lot of cat-focused behaviors.

But here's the thing. I have a really great support setup and that means that I get to keep my cat. No one has talked about getting rid of the cat or even just shutting it out of the room while that time is happening. No one has told me that the consequence of getting distracted is that I lose the cat. No one has ever so much as breathed the word consequences at me. Because I am an adult and that is not language or a paradigm we use with adults that we are treating as equals, let alone adults that we work for. Does that sound like a big deal to you? It does to me. Because this is not the experience a lot of my friends who rely on services get to have. The settings rule doesn't say anything about the cats. That's not the point. But it says a lot about quality of life. Settings rule says a lot about the way I should expect to be treated and the kind of life I should

get to have. Do I get to have an ordinary life with ordinary things? Do I get to have the things that are important to me? Does my support person see me as something to control? As a check list of tasks complete. As a large child to be baby sat? As an inconvenience to be managed? As wasting their time? Or does my support person understand that I am in charge, that they work for me, that their job is to help me reach my goals and live my life the way I want. Am I treated with respect? The answers to these questions have a very concrete impact on my quality of life. And on my ability to have a beloved pet and on a hundred other little things every day. And those little things to me and to my friends, to people who use HCBS, are everything. And that's what the rule is about. The thing is, the reason the settings rule came about is that my experience is rare. My baseline expectation that I am in charge of my life is rare. It should be common. But it's rare. It's rare because of the way that states have set up their service system. That was a policy choice. The settings rule gives us a chance to change that and make this kind of basic dignity common. But to do that, we have to look at everything. We have to look at every part of our system and we have to change things from the top down and the bottom up. And as those policy changes are happening, we have to be consulting with self advocates and consumers in the state about their experiences and recommendations at every point in the process. The rule is fundamentally about the person's experience of their services and their lives. If we aren't focused on this stuff, we aren't doing our jobs. And you can't just change a program overnight. In order to implement the rule, states have to develop detailed plans showing what changes they will be making and the state has to give people the comment on their specific plan. Again, they go back and forth to finalize their plan and every time it gets updated it goes back out for public comment. Pennsylvania is currently in the process of finalizing its plan. There may be more public comment opportunities coming your way. Keep your eyes open. As states have worked to update their community service and make sure they are providing what people need, a lot of states have run into a familiar problem. Funding. Individualized supports are usually more cost effective than group supports. But switching over how a state or provider does things can cost more up front. For example, let's talk about employment again. We know that people have better outcomes when they are working or otherwise spending the day in the community instead of spending it in a sheltered workshop. But closing down sheltered workshops and getting everyone set up with new services costs money up front. In the short-term, it's more expensive even though in the long run it's better. And many states and providers don't have that kind of money. Similarly, the settings rule says that anyone who wants to live in their own home instead of in a group home, has to have that option available. But the vast majority of states can't meet that requirement. Because they are invested most of the housing resources in group homes for years. They can make the change but need

resources to get started. Next slide? Goodbye, cat.

Senator Casey took this problem seriously. His office, led by Michael, met with advocates for months to work out a solution. It's called the HCBS investment act. It's another example of participatory policy making. It isn't just limited to helping writing the bill itself. The way the bill works is if the state decides they want a grant they have to put together a planning council. The council has to include people who use services, poo 'em who need services but aren't getting them, family members, providers and people from different state agencies. At least half of the committee has to be people with disabilities. They have to put together a comprehensive plan for what they would do with the grant, focusing on what people in the state need and once the grant is awarded, the committee is still involved in implementation. Self advocates can help shape the process every step of the way and truly make sure that the service their state offers match with people with disabilities need.

If there's one theme I hope you walk away with today it's that self advocates must be involved at every level of policy. When ASAN works on pool sees around community services we take a lot of time looking at states and individual providers but also at a national level and we look every opportunity to get this issue addressed. Interestingly enough, that's included universal health care. One of the fundamental problems many people with disabilities experience is that HCBS is disconnected from other health care. Health insurance will cover doctor visits, surgery, medications, even therapies but it doesn't cover the services and supports we might need over the long term to stay in homes and communities and live good lives. If you need HCBS, you have to go to Medicaid. Prior to 2017, when folks talked about policy, folks talked about health care reform including universal health care. HCBS was rarely mentioned. It wasn't really a part of the conversation. But after the disability community helped save Medicaid and the ACA in 2017, we had a little juice. So ASAN, along with some folks from the ARK and a few other organizations went and met with the trail offices offering three different versions of Medicaid for all. We made sure services are included in all three versions of Medicare for all that were introduced in Congress. If HCBS is part of a universal health care, that means there shouldn't be any more waiting lists. It means that everyone who needs services should be able to get them. It means that the services in Maine and in Tennessee should be equally good. And it means that people with disabilities could move between states without losing our Benoit ifs and having to start all over again. Most importantly, it means we wouldn't be confined to Medicaid. We could get services even if we worked full time, if that's what we needed. For a lot of disabled people, it would mean freedom.

Now, I'm a realist. I don't think Medicare for all is going to pass this Congress or even the next one. But that's not the point. The point is that in 2017, we established a new baseline expectation. If you try to fundamentally change our health care system, and you try to do it without people with disabilities, you will fail. And now we have established if we try to make good changes and push for things like universal health care in whatever form that may take, people with disabilities are going to be a part of that. Nothing about us without us. Regardless of whether or not it's Medicare for all, the next few years will see another attempt at health care reform. And when that comes about, access to home and community based services are going to be a part of that conversation. Period. It's not going to be easy. It's not going to be quick. But we are going to get universal access to these services over the finish line. We are going to end the waiting list. We are going to get everybody what they need. That's the goal.

So as you can see, I get pretty wrapped up about participatory policymaking. It's exciting stuff. But it's not universally beloved. This is not surprising. When a group that traditionally has been given very little power begins to speak up, they usually push for change. Certain structures feel threatened. Resistance emerges in odd places. A good example in Pennsylvania is the fight over the closure of the Polk center. At a policy and at a personal level, the closure of Polk Center is an obvious good thing. It is robustly supported by decades and decades of research and practice that show that people living in institutions do better in the community. It is supported by voices from strong self advocates across the state, many of whom are institution survivors, of Polk Center itself. Most in Pennsylvania support the closure whether led by people with disabilities, parents or providers. So why did the governor have to veto a bill that would have blocked its closure and the closure of any other institution in the state?

Well, the closure is strongly opposed by the employees who work there. It's also opposed by some older families whose family members went into the center decades ago and have lived there for most of their lives. Those families were typically told by doctors that if they loved their family member, they would institutionalize them. It's hard to hear that they were wrong. That this in fact harmed their loved one and that this time, the experts have it right. They have heard that before'

The people opposing the closure are a small minority, but they are loud. And when you listen to what they say, an interesting pattern emerges. First, they insist that this is really all about choice. Which is interesting. It's interesting because institutions are famously devoid of actual day-to-day choice. It's interesting because you don't exactly

see nondisabled people lining up for the choice of living in an institution. But they insist that we need to preserve institutions as a choice for the people who want them. So we will ask, well, who are the people who want this choice? And this is where we come to the second interesting piece of the pattern. Because they insist that the answer is, people with really significant disabilities. The people with the most significant disabilities. They want this choice.

Now this is difficult to believe for a few reasons. First of all, people with very intense needs have left Polk Center and other institutions and they are unanimous in saying they don't ever want to go back. Second of all, there are certainly current residents who say they are afraid to leave and that is understandable. Because change is scary especially for some people with developmental disabilities. And also because when you talk to these folks it becomes immediately clear that they have not actually been given accurate or accessible information about what their choice would be. Third of all, the defenders of Polk Center will say that since they are the guardians for their family members, their voice is the same as their family members' voice. Now this is obviously nonsense. To borrow some autism research jargon, that's a clear theory of mind problem. But they are right that as their family member's guardian, any choice legally is theirs. They just aren't the person that choice happens to.

The other thing they will say is that they really are speaking for the people who cannot speak for themselves, who do not have a voice. And this is interesting, too. Because it is certainly true that there are people within Polk Center who do not have a good way to communicate that other people can understand. But it's also true that we have strong research showing that there are only two prerequisites for communication. Preferences and the ability to move one muscle on your body independently. If you have that, we can find a way for you to signal yes and no. And from there, we can build out a whole communication system.

There are no voiceless people. There are plenty of people who have been spoken over, ignored, or not given an accessible way to communicate. That is a huge and urgent human rights issue. It is certainly not a reason to keep an institution open.

This rhetoric is not unique to the Polk Center closure. It's the same set of arguments used by those who oppose the settings rule, those who want to protect minimum wage and those threatened by self advocates speaking for our self and taking on a role in policy and research. The flip side of that, the idea that advocacy means speaking for those who cannot speak for himself. ASAN has always been very clear that no, that's not it. We are not speaking for anyone. We are fighting for everyone's right to speak

for themselves. We all have a voice, no matter how we express it and we are all going to be heard. That's what ASAN is about. That's Neurodiversity. That's the whole point.

That's why we support legislation led by Senator Casey to expand access to communication supports so that everyone can find a way to be heard that works for them. That's why we support alternatives to guardianship like supported decision making, which allows folks to get support understanding and making decisions without losing our legal right to make our own choices. That's why we are focused on breaking down barriers until anyone who wants to can play a role in policy and research. Until at a minimum, everyone can have a say over their own life. We aren't leaving anyone behind. Self advocacy has always been about everyone from the time the first institution survivors started working on a way to get out. It was never just about those individual people. It was always about everyone else trapped in there with them. We are never content with just our own freedom, our own participation, our own inclusion or our own power. We are not content until we get everyone. And when things get hard, we don't give up. We don't go oh, this person can't communicate, this person can't make decisions, this person is too severe or too low to be included. We go -- that's our next step. This is the next thing we need to figure out.

Researchers on the Zoom today, we need you with us on this. Every issue I talked about today from access to communication, to what good services look like is something we still need no more research on. We are eager to work with you. Come work with us. Policymakers on this Zoom, the same goes for you. No matter what your role is, if you are in a position where you are helping in any way to shape decisions about people with disabilities, I implore you to remember that even if we need help with the acronyms, we are the experts on our own lives. We absolutely must be at the table. And if you consult with us in real, meaningful ways we can do incredible things.

Thank you.

>> Thank you so much, Julia, for such an informative and passionate presentation. Hi, everyone. My name is Mimi Wong from the policy and analytic center.

>> My name is Kaitlin Miller. I am also with the center. We are going to work through questions with Julia and Michael if you are still there, please feel free to chime in with responses as well. Julia, the first question I have for you is about quality of life. Julia, you mentioned differences in quality of life based on different living circumstances. How do you define and how do you measure quality of life in the most meaningful way for autistic adults?

>> Yeah, think this is a really important issue that researchers are just starting to crack into in a meaningful way. Traditionally, quality of life has been measured by what nondisabled people think their lives would be like if they suddenly lost abilities, which is just not how disabled people see our quality of life and there is some pretty good research showing that at a qualitative level. Disabled people see their quality of life similarly. It matters to how they define quality of life for themselves. Think this is super under researched. I would like to see more work to see what the norms and the aggregate to figure out what are the most important things to autistic people. For me, proximity to my cat and ability to ride my trainer are important. The world health organization has done a lot of work on quality of life in general and I think helps, independence, safety and security, control over your day, think those things are not unique to nondisabled people. Think they apply broadly, but it would be great to get more detailed research to actually really answer that question. But that's a starting point.

>> Such a good call to action for all of us. I echo the cat comment for quality of life.

>> The next question --

>> She hasn't show up today.

>> The next question is about resource. So are there any particular resources, whether it's book, pod casts, about ableism and how to reduce or end it, that you would recommend?

>> I think if people are looking for a primer on ableism and disability, a really good anthology was published called disability visibility. By Alice Wong, a variety of walks of life that talks about ableism as a lived experience, disability, hopes for the future. It's powerful. Also contains the most powerful historical piece, a piece by Harriet Johnson who unfortunately passed away a few years ago called unspeakable conversations, which is about a disabled person arguing about the idea that their life has quality and worth and meaning and what it feels like to have to have that argument about your own life. I always recommend that people start there. The anthology goes over all sorts of writing from all different people. It's a good place.

On the opposite side, I edited an anthology called loud hands. Eight years ago. It similarly collected a lot of writings from a lot of people about ableism, what the future would look like, et cetera. You could also look there.

All right. Thank you.

>> Our next question is -- for those of us based out Universities, are there best practice models or strategies that you or ASAN recommends for how researchers can or should engage autistic individuals in informing our

processes and goals?

>> That's a great question. At a research level, there's been work coming out of the University of Oregon, yes, in Portland. The Aspire collaborative which is the academic autism spectrum partnership -- I don't remember the acronym. I'm sorry. But there are really great collaborative of autistic people and researchers including autistic researchers who have been pioneering community based participatory research in this field for the last decade. They put out a paper I think last year summarizing a lot of lessons learned and basic guidelines that people that want to start doing this can use and few Google AASPIRE, two As, they can find their resources. They are fantastic. We like working with them. There are other collaborations, ASAN's involved in a couple, but there are I -- they are one of the oldest and have done a lot of work documenting their process and procedures.

>> Thank you. We will make sure we find that link and can pop it in the chat for folks, too.

>> One of the -- I forgot this when I was talking about them. But one of the exciting outcomes of a lot of that work has been a new journal, which I am on the editorial advisory board for called autism in adulthood which has started publishing in the last couple of years a lot of the kind of research that I talked about. Sometimes community based participatory research, sometimes just research looking at adults or anyone older than five. And they have had some good articles on participatory research, as well. So it might be worth looking at that journal in general.

>> Thanks, Julia.

>> The next question is what is the most difficult thing that you encounter when trying to change policies that clearly do not benefit those with developmental disability?

>> So many challenges. I think the most fundamental challenge is the belief that I kind of naively have the belief that if you are writing policy about developmental disabilities you want that policy to be good and be good for the lives of people with disabilities but people do their work for a wide variety of motivations and sometimes it's not actually about benefiting people. And that's very difficult to counter and to work with. Sometimes it's about upholding power structures or keeping profits that have been made a certain way to continue flowing that way or about feeling good as opposed to doing good. All sorts of complex things. I think a barrier that ASAN encounters is that if a person with a developmental disability is speaking about a policy issue, then that person isn't really disabled or that person doesn't really know what they are talking about. That they have been coached or being used like a puppet by someone. And that's obviously very frustrating and really comes out of a lot ever ignorance about what development disability is, what intellectual

disability is, what people with disabilities are capable of. A lot of ableism. But it's also just, the people who train to be self advocacy were people who were institution survivors who had closed the institution in New Hampshire right before I was born. So the idea that someone can't have like a really significant disability and also have opinions about their life, was never something I needed to be taught, but I think that because so many people have not grown up around people with really significant intellectual and developmental disabilities they don't have that experience and so they are really baffled when we show up especially if we are wearing business casual clothing and we know the policy acronyms because it's our job. They don't have a mental framework for that. So a lot of our work is getting people used to that idea. As opposed to doing the actual work of discussing the policy issue we want to talk about.

>> Thank you for that.

>> So, the next question that I wanted to ask is, what is the current status of the federal committee, the question asker did not specify. I'm assuming it's the IACC. So if you could speak to that, that would be great. Thanks, Julia.

>> Do you into the nova the feel bad questioner, almost everybody who asks me the committee also can't remember the name. It is the -- I call it IACC. The interagency autism coordinating committee. The acronym doesn't even match the words perfectly. But this is a federal committee that oversees autism research spending that I talked about. The committee was reauthorized last fall when autism CARES passed. The next step was to nominate new members and the federal government would make final decisions and the committee would start meeting. The nomination process was happening, we submitted names, deliberations were coming, I don't think final decisions were made. Then COVID hit and almost anything at NIH that was not about COVID has been put down. So, it's on hold right now to the best of my knowledge. I don't think this we will see it start up again until the public health emergency is over. A lot. But it's also not targeted to that committee. -- I think I would be more frustrated about this personally if the committee was more powerful or more relevant to autistic people. We did have good nominations. A lot of different experiences including nonspeaking people so I do hope they get it together and finish nominations before the next reauthorization. But right now I think it's pretty understandable that the pandemic has taken precedent over almost everything.

>> Absolutely. Thanks, Julia.

>> We have a question, another question about resource. Parent here. My son is 21 and not particularly verbal. Is there a resource for me to find a self advocacy group he might be able to participate in? I have never

really known where to look before.

>> Can you repeat the last sentence?

>> Yeah. I've never really known where to look before.

>> I would definitely start with ASERT's website. They will have the best local resources. If you might have more success also looking at groups for people with sort of intellectual developmental disabilities broadly. Sometimes autism specific support groups are focused on people who can speak which I think is really unfortunate and not something that ASAN supports but unfortunately is sometime still a problem you can sometimes find. Sometimes groups that are the wider range of disabilities will be more accommodating. Either way your son has a right to participate and the organizer should be willing to work with you but that might be something to keep in mind.

I know that I want to say it's Temple University, I could be wrong. A couple of Universities in Pennsylvania doing really good research and practice on supporting people to communicate. It might be worth reaching out to them and seeing if A. temple's right and if I am wrong, maybe they can tell you which one it is and help your son through other methods.

>> Great. Thank you.

>> All right. I have another question. I am autistic. I have gotten pushback from parents of autistic adults who left school who are unable to fit independently and cannot find success in community integrated services as opposed to institutional services. The people providing the service can't handle their meltdowns when they become violent in the community. Ka can I say to a parent like this? Are there resources or ways to expand perspective?

>> Yeah, think that one of the misconceptions people have is self advocacy is that self advocacy is something people do when they are doing keynotes, but it's really just standing up for yourself and saying how you feel about your current situation. Saying no or having a mental health meltdown can be self advocacy. They might have an underlying medical condition that they might not have access to effective communication so this is the best way they have to express their problem. There could be other things going on. It could be that they are bored and not getting the support they need. And so, when they are given community services, those services aren't a good fit. So I first want to just say that this is really difficult and I think that it's important to encourage families to come from that place of empathy and to remember that it is difficult for you, also much, much, much more difficult for your family member and people don't do things for no reason. There's a reason that this is happening.

There's a really good resource that the thinking person's guide to autism

put out that I think was called understanding challenging behavior or something like that. It gives people a checklist to think through of things that could be going on that's causing a person to have difficulties.

But fundamentally, like that person has a right to get services, even if they are having a lot of issues and even if providers don't feel certain about how to work with them. So it would also be worth the family reaching out to the offices of developmental programs to ask for another person centered program, Ave view to determine what's not working and what additional resources to help people stabilize and have success. I think that often providers, because they got a lot of people to serve, try to do this one size fits all cookie cutter approach. It doesn't work for a lot of people. It especially doesn't work for a lot of awe 'tis Tim people and families need to say this isn't working and we need something different and they shouldn't accept oh, well this is all we offer and you are going to be taken to an institutional setting or no services if you don't accept it. The disability program should be able to help them navigate that.

>> Those are some really good suggestions. The check list sounds really helpful.

>> I'm sorry I don't remember the URL.

>> I'm sure we can find it.

The next question is how is ASAN advocating for Black autistics who -- advocating for Black autistics who are misdiagnosed and probably underrepresented in organizations.

>> That's a great question. On the research side, would he submit pretty regular comments to the committee that we talked about, talking about our research theories and one of the things we always talk about is diagnostic disparities and the need for more research. And just practice and funding to accurately assess and diagnose people. A lot of our education policy focuses on autistic kids and students of color who are more likely to be identified as having other disabilities, more likely to be restrained or the pipeline trying to right inequities and see that as a point of leverage where schools have a lot of resources, people should be correcting errors, diagnosing people correctly an connecting them to the right support. Solving racism isn't as simple as that but it's a policy area where we could have impact. We did a booklet this summer on police violence after the murder of George Floyd trying to lay that out in a more accessible way for our members. And we are a part of the leadership conference on civil and human rights which is a big several hundred organizational member organization of different civil rights organizations. They are doing a lot of work on policing and criminal justice reform and so on that we are trying to be involved in. We have had some conversation was Senator Casey's office and other offices and bills that would work on those issues.

There are a lot of different pieces on this. This is something we could talk about for an hour but off the top of my head these are areas we are working on right now. We are encouraging the community to look at racism within the autistic community and to look at how we can center and elevate autistic people of color especially Black autistic people. So we had our gala online a couple of weeks ago. As part of that, we did a panel on racial justice and Neurodiversity. We are doing those things, having those conversations, reminding people to do things differently and to give autistic people of color examples of themselves existing because they don't feel alone. The reality is autism is a part of every community. And we need to make sure that's well represented and that people can see themselves in the stories we are talking about.

>> Thank you for sharing that information across all of your efforts.

>> So I think this might be our last question and we can see how time works for us. What about the value of finding a cause for autism i.e., biological symptoms if they exist to better diagnose kids in childhood years. It's better to pivot to the school instead of dismissing them as unnecessary.

>> So, I mean I think I did do that talking about biological resources useful to autistic people as opposed to dismissing it out of hand. But the reality is, like what we have seen over and over and over again is that when research targets the biology of autism and the causation of autism, immediately, as Drexel talks about, modifiable risk factors. The so what of the research is so that we can get rid of it. That's something that many almost every study says in their funding proposal and in their abstract when they talk about their results. I think from a scientific perspective as someone who is a little bit of a geek myself I would like to know the answers to a lot of these things. But these answers don't exist in a vacuum. And the way that they get used really, really matters. So when we are talking about the biology and until we are in a place where autistic people can control what decisions get made with that research or that it's being used to better people's lives as opposed to the way it's currently being used now, I think they are very different conversations. One of the things that's been frustrating as an autistic person has been, you know, think the science is really clear even 10 or 20 years ago that a cure for autism was a not a scientifically coherent concept and the conversation has shifted, it's shifted to if we can't get rid of it, how can we prevent it. It's disheartening. We still see that today.

>> Thanks, Julia. I know that's a tough question to answer for researchers.

>> Julia, thank you so much for your time, Michael, thank you for being here. This has been a really rewarding day and such a tremendous way to

spend our morning together. For everyone on the west coast an even earlier morning. We very much appreciate everyone who spent time with us today. And we are going to be posting more information so please stay tuned with us at the Drexel autism institute for further resources. Check out the ASERT collaborative, the Philly project and the new report focused on health and health care. Julia, thank you again. Very grateful. Michael, thank you. We wish you all well in the very exciting few months we have coming up here in the U.S. from a policy perspective and look forward to our research partnerships as well. thanks, everyone.